

EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

February 2019



The Indirect Costs of IBD

page 5

There is no such thing as a perfect parent IBD and parenthood

page 6

EFCCA Members

Austria - OMCCV www.oemccv.at	Lithuania - CCLA www.draugija.info
Belgium CCV: www.ccv.be Crohn-RCUH: www.mici.be	Malta - MACC www.macc.org.mt
Bulgaria - BCUCA www.babkuk.org	Norway - LMF www.lmf norge.no
Croatia - HUCUK www.hucuk.hr	Poland - J-Elita www.j-elita.org.pl
Cyprus - CYCCA www.cycca.org	Portugal - APDI www.apdi.org.pt
Czech Republic - OSPs IBD www.crohn.cz	Romania - ASPIIR www.aspiir.ro
Denmark - CCF www.ccf.dk	Serbia - UKUKS www.ukuks.org
Estonia - EPSS www.ibd.ee	Slovakia - SCC www.crohclub.sk
Finland - CCAFIN www.crohnjacolitis.fi	Slovenia - SAIBD www.kvcb.si
France - AFA www.afa.asso.fr	Spain - ACCU www.accuesp.com
Germany - DCCV.e.V. www.dccv.de	Sweden - MOT www.magotarm.se
Greece - HELLESCC www.crohnhellas.gr	Switzerland - SMCCV www.smccv.chwww.asmcc.ch
Hungary - MCCBE www.mccbe.hu	Turkey - IBHDYD www.ibhportali.com
Iceland - CCU www.ccu.is	UK - Crohn's and Colitis www.crohnsandcolitis.org.uk
Ireland - ISCC www.iscc.ie	Associate Members:
Israel - CCFI www.ccfi.co.il	Argentina - Mas Vida www.masvida.org.ar
Italy - AMICI www.amiciitalia.org	New Zealand- Crohn's and Colitis www.crohnsandcolitis.org.nz
Luxembourg - ALMC www.afa.asso.fr/luxembourg	

Content

EFCCA News	5
The Indirect costs of IBD - European Survey	
.....	
There is no such thing as a perfect parent - IBD and parenthood	6
.....	
European Youth Group	16
.....	
Member News	18
.....	
Living with IBD	
“I want to be the voice of people with IBD”, Interview with Anna Hakala	30
.....	
News from partners	
Everything you wanted to know or didn't know about “Home Parenteral Nutrition”	34
.....	
Medical Review Corner	38
.....	

Every effort has been made to ensure that the information in this publication is presented accurately. The contents are provided for general information and should not be relied upon for any specific purpose. Descriptions of, or references to, products or publications do not imply endorsement of that product or publication. Patients should consult their doctors if they have any medical concerns. Neither the Officers of the Executive Committee nor the editor can be held responsible for errors or for any other consequences arising from the use of information contained herein. As part of its commitment to transparency EFCCA will fully comply with the EFPIA code, and other applicable national codes of practice as appropriate, which govern ethical and transparent relationships with commercial and pharmaceutical companies. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without the prior permission of the EFCCA Secretary.

Making the invisible visible

It's with great pleasure that I present you the first issue of the EFCCA Magazine for 2019 as we have some exciting news to share with you. Our board and staff has been working very intensively in recent weeks to develop our **strategy for 2019-2022**.

We are now in the process of finalizing the document and it will be presented to our General Assembly which will take place in Prague from 24-26 May 2019 in association with our colleagues from Pacienti IBD (Czech Republic).

What I can say at this stage is that we take the request and needs from our members very seriously and combined with the findings from our surveys we decided that our strategy is directed towards tackling **discrimination** that people with IBD might face. We identified specific areas where we will work on in the coming years. So, we will be very pleased to share our plans with you soon. Besides our General Assembly, another big event that awaits us in May is **World IBD Day** (on 19 May). It's a day I personally look very much forward to, as it is a day when the whole IBD community stands together in solidarity to show what it means to live with IBD on a daily basis.

EFCCA will coordinate again the global campaign aimed at raising IBD awareness by highlighting famous landmarks in the colour of purple and this year's theme will be "**Making the invisible visible**". This theme has been successfully used by our colleagues from Crohn's and Colitis UK and we hope the theme will be in line with many of the activities and plans for World IBD Day of all our members.

Within this framework EFCCA supports the European survey on the **Indirect costs of IBD** as we want to make **visible** the impact IBD has on the patients



productivity at work and other relevant costs for society. We plan to present these findings at a European policy event towards the second half of this year.

Another subject we have been working on is IBD and parenthood. This is a subject that has come up in several meetings with our members and we decided to concentrate our efforts in preparing some useful information material on the subject of maternity and IBD.

I was present at the discussions of a Focus Group meeting which involved several IBD mums, our EFCCA staff and an IBD nurse. I was amazed at the wealth of useful and insightful material the group came up with. This material will now be translated into an animation video and I look forward to seeing the final product which I believe will become an excellent tool for our community.

We are also collaborating on an interesting survey that looks into the risk of children - whose parents both have IBD - in developing the disease. To date there is only scarce literature about this subject and we believe that more studies and research into this matter are essential as this is a very important subject for many people with IBD.

The study is being carried out by Dr Joana Torres from the Gastroenterology Department at the Hospital Beatriz Ângelo (Portugal) with the support of the European Crohn and Colitis Organization. She has presented with great enthusiasm the survey during the World Symposium on Research that we organized last year and I urge our members to spread the news and support this important work.

In this issue you will also read about some amazing initiatives that our members have carried out in recent months. I feel very much inspired by the strong commitment and creativity of our members to support people with IBD.

And it's not only our members that are working hard to make life for people with IBD better: in our *Living with IBD* section you will read about how one woman, Anna Hakala from Finland, is doing an incredible job in helping other people with IBD to better come to terms with the disease.

Having had herself a very difficult IBD journey - it took her 19 years to get diagnosed! - she wants to let other people know that they are not alone and that there is a support network out there to help go through those feelings of desperation and fears that many of us might face.

As you can see there are some exciting months ahead and going through the next pages you will find plenty of stories showing you the enthusiasm, commitment and hope we can find amongst the IBD patient community. We want to make our voices heard and to constantly fight for a better quality of life of people living with IBD.

Let's make this daily work visible and show to the whole world that UNITED WE STAND!

Salvo Leone
EFCCA Chairman

The Indirect Costs of IBD

EFCCA is supporting a new study which aims to assess the impact of Inflammatory Bowel Disease (IBD) on the patients' productivity at work and other relevant costs for society. We believe such data will provide patient associations with a powerful tool to discuss with policy makers on how to improve the situation for people with IBD in particular as concerns discrimination at the work place.

It is fairly easy to calculate the medical costs of a disease, i.e. the costs for medication, hospitalization, devices, staff costs etc.. This is less the case with the indirect or the *invisible costs* as they are far more difficult to calculate even though they might make up a huge proportion of the overall costs.

Crohn's disease and ulcerative colitis are chronic diseases which have a significant impact on a patient in terms of his/her ability to work, sick leave, productivity etc. Therefore the **indirect Costs of IBD** study wants to find out about these unknown costs. Such costs include the lost earnings not only of the patient with IBD but also of family members who have lost working days to take care of an IBD patient as well as the costs of reduced employment and unemployment.

The study is carried out by the Institute of Public Health, Jagiellonian University Collegium Medicum in cooperation with patient associations from European countries under the joint patronage of the European Federation of Crohn's and ulcerative Colitis Associations (EFCCA). It's available on-line in 11 EU languages and participation is fully anonymous. The results will be available for EFCCA members and published in research journals.

Why is this survey important?

EFCCA believes that collecting and analyzing the economic impact IBD has on our society will help us and our members to better understand the implications and work more effectively with policy decision makers in order to tune and prioritize social, employment and

health policies as well as other interventions.

Policy measures that can be implemented at the work place or other areas related to employment and that are taking into consideration the specificities of people with IBD might result not only in a better productivity level but also an overall improvement in the quality of life of the IBD patient.

“EFCCA believes this survey will help to work more effectively with policy decision makers to better tune and prioritize social, employment and health policies”

Given the budget constraints that many governments in Europe and elsewhere are currently facing, such evidence based information that the indirect costs survey will reveal will make it an important tool for ensuring the better allocation of resources. To participate in the survey follow this link: www.ibdcosts.eu

For more information please contact the EFCCA office.

There is no such thing as a perfect parent - IBD and parenthood

Deciding to become a mum - or father for that matter - is certainly something that requires a lot of careful thinking and reflection. Will I be a good mum/dad? Am I ready to have children? How will it change my life? Can I afford it? - these might be some of the questions that are going through your mind. Now imagine you have a chronic disease such as Inflammatory Bowel Disease? That brings along a whole new set of questions and doubts!

Unfortunately, IBD often affects young people during their child-bearing years. So, for someone who has IBD all the usual questions about parenthood take on a new dimension as he/she will be wondering how their disease will affect their likelihood to conceive, their pregnancy and eventually being a parent.

There will be concerns about the potential side effects of IBD medications taken during pregnancy and/ breastfeeding, there will be the issue of having a natural birth or a C-section, on how to cope with being a parent whilst having a flare up, or whether the disease could possibly be passed on to the child.

It's a highly emotional time and ideally the prospective parent should have an understanding partner, good family support network as well as a good healthcare team at hand with whom to discuss specific doubts and concerns.

EFCCA believes that patient associations can also provide some support by providing information and raising awareness around some of the concerns parents with IBD might face.

With this in mind EFCCA is currently working on an exciting project that aims to raise awareness about what it's like to live with IBD (i.e. Crohn's disease and Ulcerative Colitis).





Participants at the focus group meeting which took place in October 2018, Brussels

We have produced a series of animation videos that help people through their IBD Journey. These videos aim to equip people with practical advice and relevant information and hopefully will bring about positive changes to the way they cope with their disease.

We are now working on a video animation that looks at the issue of **IBD and maternity**. As part of this process we have organized a focus group meeting involving four “IBD mums” as well as a specialist IBD nurse in order to discuss common concerns and personal experiences that appear whilst being pregnant and being a mum.

For example one point made during the discussions was the importance of a cooperative healthcare team involving the gynecologist, IBD specialist and possibly an IBD nurse in countries where these do exist.

Another point raised by all mums was a constant worrying about not being a good mum because of tiredness or other problems linked to IBD, so one of the key messages from the video will be that there is **“no such thing as a perfect parent”**.

These and many other points raised during this meeting will now be worked into a script for the video animation which is expected to be published next year.

We are very excited to see the final product and would like to thank the four mums and nurse for their active participation in this focus group.

“As part of this process we have organized a focus group meeting involving four “IBD mums” as well as a specialist IBD nurse”

We also appreciate the support that the project is receiving from the pharmaceutical company Janssen. For more information about the IBD Journey animation series please visit:

<http://www.efcca.org/en/projects/my-ibd-journey-animation-series>

Isabella Haaf
EFCCA Deputy Director

Getting the real picture IBD and parenthood

There is still no known cause of IBD though it is linked to a combination of hereditary, genetic, and/or environmental factors. A positive family history of IBD remains the strongest risk factor for developing IBD. For someone with IBD who is thinking about having a child hereditary is an important factor to consider. EFCCA therefore believes that more studies and research into this matter are essential and beneficial to the wider IBD community.

There is only scarce literature about the risk of children whose parents both have IBD in developing the disease. Small studies carried out in 2001 have suggested that children of couples where both parents are affected by IBD represent the first-degree relatives with the highest risk of developing IBD. However, these estimates were based on small studies conducted in high risk populations for developing IBD (Jewish ethnicity and individuals from a high-incidence area for disease).

Given the fact that IBD increasingly affects young people especially during the child bearing years EFCCA strongly supports the survey *“The phenotypic features of couples with IBD and their offspring”* which is being carried out by Dr Joana Torres from the Gastroenterology Department at the Hospital Beatriz Ângelo (Portugal) with the support of the European Crohn’s and Colitis Organization.

The survey aims to better characterize the sub-group couples with IBD and their children and to describe the frequency of couples with IBD and the frequency of the disease in their offspring. It hopes to provide more accurate risk estimates to couples and prospective parents living with IBD and to improve pre-conception counselling.

Furthermore, identifying individuals from families at high risk for developing IBD could offer the possibility to create a “high-risk” cohort for future studies,



which could have important contributions to our understanding about disease pathogenesis.

The survey is available on-line in English, French, German, Spanish and Portuguese. All information collected in the survey will be used for research purposes only and will only be shared between the investigators involved. Data will be de-identified and stored on a secure server with restricted access.

We encourage any suitable candidates to participate in this exciting project. For more information and to access the survey please follow this link:
<http://www.efcca.org/en/survey-couples-ibd-and-their-offspring>

EFCCA Strategy

Work in progress

EFCCA board members have been preparing a new strategy for EFCCA to cover the period 2019-2022. The new strategy will consolidate the good work that has been done so far and take into consideration the growing position of EFCCA both in the European and international arena as well as incorporating the needs and priorities of its members.

The EFCCA board and staff met for the first face to face Executive Board meeting in the EFCCA offices in Brussels from 16-18 November 2018, following the election of Salvo Leone as new EFCCA chairman during the General Assembly in Bucharest (25-25 May 2018).

The first part of the board meeting was dedicated for dealing with some operational and daily management issues which was then followed by the main discussions that centered around developing a new strategy for EFCCA for the next four years. The new strategy will make sure to consolidate the work that has been done so far but will also take into consideration the changing realities and the increasing role of EFCCA as a reference point of the international IBD community and stakeholders as well as the needs and priority actions established by our members.



A follow up meeting to discuss the first draft of the strategy took place in January (11-13) 2019 and the strategy paper is now being finalized and will be presented to our members in time for the General Assembly 2019 for final endorsement.

Latest science in IBD

UEG WEEK

As every year EFCCA, participated at UEG WEEK which took place from 21-24 October 2018 in Vienna, Austria. It was a great occasion to catch up with physicians, other healthcare providers and stakeholders as well as to learn about the latest developments, research and state-of-the art clinical practice. Some of the interesting topics presented during the Congress and that were related specifically to IBD dealt with:

Advances in IBD

In recent years additional options for treatment of moderate-to-severe IBD therapies have been provided for patients that have failed to respond to anti -TNF treatment. Several presentations and abstracts during UEG Week showed updates on such novel treatments such as targeting Janus kinase (JAK) signalling, MAdCAM-1-mediated adhesion and interleukin IL-23

to name a few.

A research presented by Dr Timna Naftali generated great interest. In the first study of its kind, cannabis oil has been shown to significantly improve the symptoms of Crohn's disease and the quality of life of sufferers but, contrary to previous medical thinking, has no effect on gut inflammation.

Sharing of real-world clinical practice

Although there have been various clinical trials that have looked at the efficacy of new biologics used in ulcerative colitis and/or Crohn's disease, there were some interesting presentations made at UEG WEEK 2018 looking at data of real world effectiveness of several treatments, such as for example the

presentation of a French nationwide prospective study of CT-P13 as well as a study presented by Dr Karima Farrag from Goethe University, Frankfurt, Germany who shared results from a retrospective analysis of patient records from three German IBD centres.

Resources required for IBD management

A series of presentations and posters at UEG Week 2018 explored resource utilization and the costs associated with IBD management.

This topic is of particular interest to EFCCA as we have recently launched, together with our Polish member, J-elita and the Institute of Public Health, Jagiellonian University Collegium Medicum a survey

on the indirect costs of IBD with the aim to assess the influence of inflammatory bowel diseases on the patients' productivity at work and relevant costs for the society (see page 5).

If you would like to find out more about UEG WEEK please check out their website and their UEG Week Congress Review 2018 www.ueg.eu

Symposium “Working together to improve the quality of patient care in IBD”

During UEG Week several satellite symposia took place that offered insights into IBD management and treatment options.

Our CEO Luisa Avedano participated as speaker at the Symposium “Working together to improve the quality of patient care in IBD” which was organized by the pharmaceutical company Pfizer on 21 October 2018.

Together with another patient representative from Canada, she presented the patient perspective of the findings of the UC Narrative survey that looked at

several aspects of living with UC, including day-to-day disease impact, disease management, goal setting, and communication.

Highlighting one of the findings of the survey that showed that an alarming figure of 42% of people with UC regretted not telling their physician more about their concerns, Luisa Avedano called for urgent action to bridge the gap between patients and physicians and stressed that patient groups can play an important role in this.

For more about the UC Narrative please read the article on page 13.



Panel speakers during the symposium, 21 October 2018, Vienna

World IBD Day 2019

Making the invisible visible

World IBD Day is celebrated each year on 19 May. It's a day that unites people worldwide in their fight against Crohn's disease and ulcerative colitis, known as Inflammatory Bowel Diseases (IBD) and to show what it means for over 10 million people to live with this disease on a daily basis.

World IBD Day is led by patient organisations representing over 50 countries on five continents. In recent years EFCCA has coordinated a global campaign aimed at raising IBD awareness by highlighting famous landmarks in the colour of purple alongside the organisation of local events on either the 19 of May or around that date. In some countries the whole month of May is used to raise IBD awareness.

This campaign has been highly popular not only amongst most of our members but also other IBD stakeholders worldwide and we have seen a growing involvement and interest. In 2019 we will continue our efforts around this campaign under the theme "making

the invisible visible".

Making the invisible visible is about showing different aspects about IBD that are not so evident to the public. For this purpose and within the framework of World IBD Day, EFCCA is supporting a survey on the Indirect costs of IBD. This European survey which is being carried out by the Institute of Public Health, Jagiellonian University Collegium Medicum (Poland) in cooperation with patient associations from European countries under the joint patronage of EFCCA aims to assess the impact of IBD on the patients' productivity at work and other relevant costs for society.

We believe the findings of the survey will be of interest to both

national and European policy makers and will allow EFCCA and our members to work more effectively with relevant policy makers. Following the elections to the European Parliament which will take place in May this year, EFCCA will address Members of the newly elected European Parliament in order to present the findings of the study and it is foreseen to organise an event including a group of MEPs and other relevant EU officials towards the second half of 2019.

The hashtags that we will be using this year for our campaign are: **#makingtheinvisiblevisible** and **#worldibdday2019**

For more information please contact the EFCCA office.



UC Narrative: A Global Effort to Create New Resources for People Living with UC

“The UC Narrative survey gives us important new perspectives that build on previous research about the quality of life impacts of UC. One of these is the fact that it shows people living with UC that they are not alone. There are thousands of others having the same experiences, looking for resources and support. People living with UC must be empowered to speak up and encouraged to find help and hope.” Luisa Avedano, EFCCA CEO.

As the incidence of Inflammatory Bowel Disease (IBD), including ulcerative colitis (UC), continues to rise, many organisations dedicated to supporting people living with these chronic conditions are also seeing an increase in patients asking for support and information. However, a lot of patients, families, and caregivers do not know resources like these are available.

The UC Narrative initiative is hoping to help change that. For almost two years the Global UC Narrative Advisory Panel, comprised of EFCCA and other patient organisations, people living with UC, gastroenterologists (GIs), IBD nurses, and psychologists, has worked together to better understand the tremendous burden of UC on people’s lives - and to ultimately help decrease that burden.

The first project in the UC Narrative initiative was a global survey of

1,254 gastroenterologists and 2,100 adults living with primarily moderate-to-severe UC from 10 countries: Australia, Canada, Finland, France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States.

The survey explored a range of topics that may influence quality of life for adults living with UC, including day-to-day disease impact, disease management, goal setting, and communication.

Key findings were released in collaboration with EFCCA around World IBD Day 2018. This year, the UC Narrative initiative is expanding to even more countries, adding to the wealth of existing local and global data about the impact of UC. The UC Narrative Global Advisory Panel will continue to work together to turn insights from the UC Narrative survey into relevant solutions or programs that can help make a difference in the lives of people living with UC.

Check out some of the key findings from the UC Narrative global survey below. For more information about the UC Narrative, including additional global survey findings, visit Pfizer.com/UCNarrative.

This project has been supported by the pharmaceutical company Pfizer.

Altered lives, altered choices

The results from the UC Narrative global survey highlighted how deeply the disease can influence the lives of adults living with UC and suggested that some people living with UC accept certain UC-related symptoms, like abdominal pain, as a part of a new reality that they can’t change.

67 percent of adults living with UC strongly or somewhat agreed that they often felt like they spend more time in the bathroom than anywhere else. Additionally, 65%

of adults living with UC strongly or somewhat agreed that they felt like their disease controls their life rather than them controlling their disease.

Strikingly, the survey showed that 67% of patients who said their UC was in remission, meaning their disease is controlled with few to no symptoms, still reported using the bathroom quite often, especially on their worst day, as compared to those who said their UC was not in remission.

Surveyed adults living with UC estimated missing, on average, anywhere between five and 33 events (e.g., days of work or school, social events, travel plans, or child events) in the previous 12 months. 68 percent of adults living with UC strongly or somewhat agreed that they felt like they would be a more successful person if they did not have UC; while 51% of surveyed GIs strongly or somewhat agreed their patients would approach their school or career differently if they did not have UC.

Concerns left unspoken, resources left untapped

The survey also suggested that many adults living with UC aren't comfortable discussing certain topics with their GIs, and that both patients and GIs wanted more educational and support resources:

- 84% of adults living with UC strongly or somewhat agreed that UC is mentally exhausting, and nearly one-third of adults living with UC said they wished their GI

better understood how UC affects their mental health. However, 51% of GIs said they never discuss the impact of UC on their patients' mental/emotional health.

- 32% of adults living with UC said that UC having less impact on their sex life and personal relationships was important to them. Yet, 55% of adults living with UC strongly or somewhat agreed that they don't feel comfortable talking about their sex lives and personal relationships with their GI - and most GIs didn't feel this is one of the top three topics important to prioritize during routine appointments.

Additionally, gaps in communication and education resources identified by the survey showcase some reasons why it may be difficult for some adults living with UC to challenge aspects of their new reality.

- 46 percent of adults living with UC strongly or somewhat agreed that they worried that if they ask too many questions, their GI will see them as a difficult patient and it will affect the quality of care they receive.

- 84 percent of physicians strongly or somewhat agreed patient organisations are important to the management of UC - however, 48% of GIs said they recommend patient organisations to fewer than half of their patients.

About the Global UC Narrative Survey

The UC Narrative patient survey

was conducted online and via telephone between August 2017 and February 2018, among 2,100 adults ages 18+ residing in Australia, Canada, Finland, France, Germany, Italy, Japan, Spain, the United Kingdom and the United States.

Patients self-reported that they had been diagnosed with UC and had their diagnosis confirmed by an endoscopic procedure, did not have a colectomy, had visited a GI office in the past 12 months and had taken prescription medication for their UC; patients who reported taking only 5-ASA (5-aminosalicylic acid) medications were excluded.

The UC Narrative physician survey was conducted online and via telephone between August 2017 and February 2018, among 1,254 physicians residing in Australia, Canada, Finland, France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States.

To qualify for participation, physicians must have seen at least 10 UC patients per month, with at least 10 percent of those patients currently taking a biologic treatment for UC.

For more information please visit: Pfizer.com/UCNarrative



abbvie

People. Passion. Possibilities.®

We are proud to partner
with EFCCA

Abbvie sa/rv-BEGEN180416(1)-Sept2018



Immunology

Gastroenterology
Rheumatology
Dermatology



EFCCA retains full
independence in terms
of content & editorial
control of this magazine.

abbvie.com

IBD and stress

First of all, the EFCCA European youth group wishes you a happy and healthy 2019! We are going to be continuing to raise awareness of taboo subjects to ensure we work on breaking down barriers in conversation around these topics.

By sharing these articles, we will help to support and reassure people with IBD and their families and friends that they are not alone as well as possibly providing answers to questions they might not have been able to ask anyone before.

Mental health is a very important topic which we have previously mentioned in other articles. We decided this time we would talk about stress and how it may affect the conditions, as well as ways you could try and combat stress which also helps with your mental health.

What is Stress?

Stress is the human body's response to a situation that poses demands, pressure or even excitement. In the event of a stressful situation, the body reacts by releasing hormones, which help to prepare it to act. This is known as the Fight or Flight response and is responsible for the physical reactions experienced during stressful situations. Reactions which you may experience could be sweating or an increased heart rate.

A number of situations could cause stress, these can include common day to day activities like being stuck in traffic or having to give a presentation at school, college or work. Bigger life events such as moving to a new house, bereavement or even changing jobs also cause stress.

It is very common to experience some level of stress

trying to meet the demands of day-to-day lives. Acute stress is quite common and can be easily managed but also tends to be short lived. It is known that having acute stress in short bursts can have a positive effect on us. This because it motivates us, allows us to feel excited but also it can help us avoid danger. It is when we are exposed to acute stress for a prolonged time when it can have a negative effect on us.

Although stress doesn't cause Crohn's Disease or Ulcerative Colitis, it can lead to flare-ups and relapse. Managing stress is one way for you to minimise the effects of the conditions have on your life.

By getting the correct treatment and managing your stress levels, you can continue living a healthy, fulfilling life.

What are ways of managing Stress?

Everyone has different ways of managing stress that is evident even within the European Youth Group. See below some examples of how we like to manage our stress.

1. [Practicing Yoga](#)
2. [Meditation](#)
3. [Bullet Journaling](#)
4. [Keeping a diary](#)
5. [Finding a hobby you enjoy e.g. Swimming, Running, Singing, Reading](#)

My name is Martin, I am the French delegate in the EFCCA Youth Group and European Patient's Forum representative.

As my working days can sometimes be very stressful, I often practice things such as meditation and sophrology. This allows me to create a spiritual bubble around me to cut myself from the outside as much as possible.

The point is to forget everything that troubles you for a moment and refocus on yourself and your fundamental needs. That can be done with breathing exercises or by listening to relaxing music. It is a very relaxing and a simple way to keep yourself from being overwhelmed with stressful days.



My Name is Selina and I am 21 years old. I've been living with Crohn's disease since 2015. My tasks at EYG are to help and support others in their projects.

I help manage my stress by immediately linking negative events with positive things to create a psychological balance. So like a displacement of the stress factor.

I also do breathing exercises to avoid completely concentrating on the stress or pain it causes me.



We hope people understand that feeling stress is not necessarily something bad and can actually have a positive impact, but that it is the long term stress that is bad and that it is important to be aware of what might make you stressed so you can prevent any long term negative effects on your condition.

It is ok to talk about stress and how you are feeling.

Remember feeling stressed is a normal reaction for everyone which we all experience.

We are always looking for new topics to talk about to ensure we stay relevant to what subjects are wanted to be discussed.

If you have any ideas of what you want to see in our next article, please email: efccayg@gmail.com

Romania

Small stories with big heroes

Within the framework of our Patient Forum 2018 project our IBD association ASPIIR recently started a new activity with a special focus on IBD children. We organized a meeting with our youngest IBD patients and their parents from Timișoara (Western part of Romania) to learn more about Inflammatory Bowel Diseases and to help them better understand the disease and daily life with IBD.

Parents had the chance to talk to the IBD pediatrician Oana Belei from the “Loius Țurcanu” Emergency Clinical Hospital for Children as well as to the gastroenterologist Adrian Goldiș from the “Pius Brinzeu” Emergency Clinical Hospital Timișoara. They learned about their children’s care management, IBD evolution and perspectives for children with IBD but also about the time when their children would be switching from the pediatrician to the specialist for adults.

We worked separately with the children. A professional storyteller brought the children and adolescents into the world of therapeutic stories by challenging them

to define their fears and making them aware that there are people around (such as family, friends) who can support them in their difficult times.

The story session aimed at increasing the youngsters’ self-confidence and expressing their fears during difficult moments (i.e disease acceptance, treatment, surgery) and ultimately to make them understand that they are not alone! At the end of this event we had prepared a little surprise for the children: they received some small Santa Nicolas gifts.

Isabella Grosu,
ASPIIR



UK

New CEO joins the charity - Incoming Executive is on a mission to raise awareness of gut conditions

Crohn's & Colitis UK is delighted to welcome Sarah Sleet as its new chief executive. Sarah will commence her role in March, and joins the charity from Coeliac UK, where she was CEO for 13 years. She replaces David Barker, who stood down from the charity last September.

Sarah Sleet is an experienced and successful Chief Executive has worked with a broad range of health and patient groups and European patient organisations, as well as government advisory and research bodies.

She has also built expertise in education, social and economic policy, scientific research, income generation and campaigning.



Sara Sleet has been appointed as new Crohn's and Colitis UK CEO

Rising star receives fellowship award

The first Richard Driscoll IBD Research Fellowship has been awarded in memory of Crohn's & Colitis UK's former chief executive and tireless supporter.

Neil Chanchlani has been funded to complete a research doctorate at the University of Exeter looking at why some people with Crohn's or Ulcerative Colitis respond well to specific medicines while others fail to respond or experience unpleasant side effects.

Neil says: "We're looking at the response patients have to a variety of medicines, in particular the anti-TNF drugs infliximab and adalimumab."

"One of the reasons patients develop loss of response is because they build up an immune response to the drug. Instead of recognising the drug as a medicine,

the body sees the drug as a potential threat and tries to block it from working.”

The Predicting Anti-TNF Therapy in Crohn’s Disease study (PANTS), led by the team in Exeter, aims to look at patient, disease and medicine-related factors associated with drug response. The study has been under way for three years and initial results have been presented at an international congress in Europe and the United States in 2018. Neil explains that the data acquisition is almost complete, thanks to the massive efforts of UK gastroenterologists, research nurses and patients from across the UK, with vital past Crohn’s & Colitis UK funding.

“It’s now for myself and the team to start analysing the vast amount of data collected” says Neil, who previously worked as a paediatrician in London. “Importantly, this project includes working with data from a large number of children and young people with IBD”. “I have always been interested in working in paediatric IBD because the majority of patients are teenagers, who are going through a very uncertain type of life stage - the transition between childhood and adulthood. Often, young people have a huge struggle towards adulthood and if you add a chronic disease on top of that it can often derail them.



Neil Chanchlani has been awarded the Richard Driscoll IBD Research Fellowship

Iceland

“Can’t wait card”

We are happy to announce that our IBD association CCU has recently launched a “Can’t wait card” as a new service for its members. The card is aimed at facilitating easier access to toilets in case of emergency situations.

We are happy to announce that our IBD association CCU has recently launched a “Can’t wait card” as a new service for its members. The card is aimed at facilitating easier access to toilets in case of emergency situations. Such a toilet access card or “Can’t wait card” has been on the CCU’s project list for a long time

and through our work with EFCCA we have seen that many of our European colleagues associations issue such cards in their own countries and we believe that a well presented card and generally known for what it stands for can make life easier for those with Crohn’s disease and Ulcerative Colitis.

Our board members had hoped that it would be possible to design a common back cover in English that all EFCCA member associations could use if they wanted to, and thus the card could be widely known abroad. Unfortunately this is still not the case but in the meantime our CCU association has launched the much awaited card and distributed it to its members. Natasa Revekka Theodosiou, Deputy President of Cyprus Crohn's and Colitis Association and EFCCA Board member has kindly designed the purple logo on the English back cover.

The Icelandic Ostomy Association also has a toilet

access card for its members and the two associations decided to work together on the presentation of these cards in collaboration with the Organization of Disabled Iceland and the Federation of Trade & Services. Presentation posters with pictures of the cards and short texts in three languages were distributed in stores and with various service providers. The CCU association also undertook a Facebook campaign and did a radio interview about this initiative.

We hope that this card will give our members easier access to toilets in emergency situations!

The 2018 Galien award for the “MICI CONNECT” e-health platform

The 2018 Galien award medal in the e-health category - Mobile apps and websites - was granted to afa CROHN RCH France. Afa, as a patient association, was granted the award for its digital interactive project, “MICI CONNECT” (IBD Connect), soon a year old with now over 4500 users, composed of patients, their friends and family and medical professionals.

The Galien Award, founded in France in 1970, and world renowned, distinguishes recent and remarkable health innovation (in all existing therapies and in emblematic research) made available to the public. This award contributes, in particular, to promoting and activating health research, encouraging the laboratories and teams who can make the advances in medicine.

It honours the exceptional innovations in all fields pertaining to health: treatments, medical devices, E-health as well as patient support. This prestigious reward is a valuable label, increasing awareness to IBD through “MICI Connect” and to the patient association, afa CROHN RCH France, to ensure more and more IBD patient support.

For more information on “MICI Connect”, see the February 2018 issue of the EFCCA Magazine, page 25.



Representatives from afa Crohn RCH France receiving the Galien award. From left to right: Anne Buisson, Marion Windels and Eric Balez.

France

Microbiota in the spotlight

Without a doubt, microbiota is the star of last year and for 2019 too! Formerly called intestinal flora, everyone is now curious to learn how this little world of wonders is the center of a number of research studies, in particular around IBD.

So, it has become the subject of a new documentary film...as well as an exhibit dedicated exclusively to this complex part of the body! “Explique-moi le microbiote...” meaning: please explain what microbiota is...a film which says it all.

Following the first two films, “Explique-moi les essais cliniques” (Please explain clinical trials), “Explique-moi les biothérapies” (Please explain what biotherapies are), Afa CROHN RCH France has released a new documentary film: «Explique-moi le microbiote» (Please explain what microbiota is), to better understand these invisible hosts present in our body. Today, microbiota is offering fabulous perspectives for greater care at the heart of some promising research in IBD. That is the subject of faecal transplant presented by Professor Harry Sokol, gastroenterologist at the Saint-Antoine Hospital in Paris, very simply explained in the film.

The film is pedagogical and simple to follow. It was made by Afa's Vice-President, Eric Balez, and Gautier Isambert. Over 52 minutes, this invisible world is revealed making each one of us a unique individual!

The film's premiere took place on 12th December in the auditorium of the Cité des Sciences et de l'Industrie at the La Villette Park, in the north east of Paris in the presence of 200 members and friends of Afa. Afa had the pleasure of the visit and presence of Daniel de Bast, President of the Belgian association, RCUH. Another showing will take place with a debate following the film on 21st February 2019. Professor Harry Sokol was and will be present to further explain and discuss this vast and exciting subject. Throughout 2019, Afa will organize showings all around France to the general public as well as to patients and their friends and relatives.





Right to left: Alain Olympie, Director afa Crohn RCH- France, Professor Harry Sokol and Professor Joel Doré (INRA) during the launch of the new documentary film

LE MICROBIOTE exhibit

Let's not forget that wonderful book "GUT: The Inside Story of Our Body's Most Underrated Organ", written by Giulia Enders and illustrated by her sister, Jill Enders...

The exhibit at the Cité des Sciences in Paris opened early December and will be on until March 2019. Based on Giulia Enders book and her sister, Jill's illustrations, LE MICROBIOTE exhibit is not only instructive, but fun, funny and offers so much new information about how our intestine works.

Afa is one of the partners of the exhibit. From seeing how digestion takes place to learning about the impact microbiota has on the immune system and human behaviour, children as well as adults can better understand the workings of this second brain and feel concerned about their health.



Malta

MACC strives to gain awareness in Malta

The Malta Association of Crohn's and Colitis has organised a successful event on 19 October 2018 which was held at the Palace of the President of Malta in San Anton, Attard. The seminar addressed latest developments in Crohn's and Ulcerative Colitis.

Three proficient speakers were invited to deliver presentations, who focused on the latest management for IBD patients, the psychological aspects of IBD and IBD in paediatrics.

The Seminar, which was very well attended by patients, carers and medical personnel was also attended by the President of Malta who honoured the participants and MACC with her speech and promised her support towards MACC and its aims.

MACC notes with satisfaction that the three major TV stations in Malta covered extensively this successful event and other media invited MACC to be interviewed. Such media coverage was beneficial to create the necessary awareness of IBD.

MACC also participated in a half day Exhibition for NGOs which was held in the capital city of Malta, Valletta. This was an opportunity for MACC and other NGOs to meet with the general public. MACC took this opportunity to explain about IBD and how MACC can help people suffering from Crohn's and Colitis.

Both events helped the MACC Committee to gain the necessary awareness of IBD with the general public, as well as to defeat the taboo that exists in Malta.

The MACC Committee is fully committed to continue working on other events which would be organised in the near future.

Josef Busuttill,
MACC Chairperson



Seminar Audience



President of Malta (H.E. Marie Louise Coleiro Preca)



Chairperson of MACC addressing the participants

Spain

First hunters at WhatsApp

The first working group of “hunters in Whatsapp” was constituted during the training #SaludSinBulos (meaning health without hoaxes) organized by ACCU Spain and in collaboration with the initiative #SaludSinBulos.

During two days, (16-17 November) representatives of associations of people with Crohn’s disease and ulcerative colitis from all over Spain participated in a training aimed to provide representatives and board members with theoretical-practical notions on communication and dissemination of objective, truthful and quality health information.

The #SaludSinBulos training is the first action of the collaboration agreement between ACCU España and the #SaludSinBulos initiative that aims to combat health hoaxes on the Internet.

“The Internet is a very powerful and valuable instrument, but sometimes the excess of information, sometimes erroneous, generates uncertainty and confusion in patients. In the training we learned to detect informative hoaxes so as not to give them

repercussion, thus contributing to the dissemination of quality and contrasted information on the net in a coordinated way, taking advantage of the ACCU network of associations” explained Julio Roldán, president of ACCU Spain.

For Carlos Mateos, coordinator of the initiative #SaludSinBulos “associations are the key to curbing health hoaxes, as they can contribute to empowering patients, so that they can rely on truthful sources and contrast with their health professional. An empowered patient is a collaborative patient, more adherent to treatment. With ACCU Spain we have gone one step further, and that is to train representatives of local associations so that they can act as hoax deactivators, like hunters, in their environment. The hoaxes on Crohn’s and ulcerative colitis that have been dismantled by health professionals will be transmitted



Participants of the first workshop



Some of the participants of the first workshop, from left to right Roberto Saldaña (Director, ACCU Spain), Carlos Mateos, Carina Escobar y Pablo Bella

to this network of representatives and they will be able to spread this information through their Whatsapp and social networks, becoming references for other patients". For the last three years ACCU Spain has been committed to promote training meetings

for its staff and boards of directors, professionals, collaborators and volunteers of the associations thus generating opportunities for participation among its various entities.

Participation in the GETECCU Meeting

ACCU Spain participated in the XXIX Meeting of GETECCU, the Spanish working group on Crohn's disease and ulcerative colitis, which took place on October 5th and 6th in Madrid and was attended by nearly 400 participants.

Julio Roldán, president of ACCU Spain, presented the patient's point of view in the round table "Perspective of participants in the process of patient care: What do we mean by therapeutic success?" Next to him were two specialists in inflammatory bowel disease: Dr. Mariam Aguas of hospital La Fe in Valencia providing the doctor's point of view, and nurse Mercedes Cañas of the San Carlos Clinic in Madrid with the point of

view of the infirmary. Between the three speakers an interesting and complete vision of the question was obtained.

Other outstanding conferences of the meeting were those that dealt with current issues such as the review of the management of specific situations ("the adolescent and the elderly").



Panel discussion during the GETECCU Meeting, 5-6 Madrid 2018

Italy

Survey on Biosimilars

The Italian IBD association A.M.I.C.I. Onlus and the Italian Group for the study of Inflammatory Bowel Disease have presented the data obtained from a recent survey on knowledge and use of biosimilar drugs. Results show an alarming lack of information about biosimilar drugs. The scientific community and patient organisations deem that an awareness campaign is undelayable in light of the development of the new innovative drugs.

Biosimilar drugs are safe and have great effectiveness and quality: as highlighted by a recent proposition paper by AIFA (Agenzia Italiana del Farmaco: Italian Drug Agency), these drugs grant equal access to treatments and play a key role in healthcare cost sustainability and therapy innovation.

However, less than 50% of patients (46.3%) know about the existence of this treatment, whereas the vast majority has either never had any information about biosimilar drugs or declared to know nothing about it (respectively 45.1% and 8.5%). Furthermore, 73.9% of patients have no clear idea about the similarity between biosimilar drugs and their originator; only 10.6% of patients think that they are equal, whereas 9.2% think that they may be less safe and 12% think that they may be less effective.

For this reason, the use of biosimilar drugs is still extremely limited: only 15.7% of patients are currently being treated with biosimilars, while 14.2% have been treated with them in the past.

Knowledge about these treatments is still scarce; furthermore, patients are currently lacking sources of

proper information: less than two out of ten patients (18.9%) currently in treatment with biosimilar drugs declared that they signed an informed consent form.

“A little more than 1 out of 10 patients is being treated with biosimilar drugs”

“Barely 1 out of 2 patients has been informed about their availability”

A **survey made** by A.M.I.C.I. (IBD Patients Association) in collaboration with the *Italian Group for the study of Inflammatory Bowel Disease* (IG-IBD) involved approximately 1.800 IBD patients (72% treated in hospitals, 23.4% in universities and only 4.7% in private centers) from different Italian regions.

Survey data. The data highlight many problems regarding the knowledge about biosimilar drugs and the similarity to their originator. 57.6% of patients deem their own knowledge about biosimilar drugs as insufficient; 30.1% think to have been sufficiently informed; only 9.6% feel they are knowledgeable about them, while 2.5% believe to have excellent knowledge.

It is important to highlight that patients who feel sufficiently informed about biosimilar drugs (41.1%) are more likely to consider their employment as a useful resource to reduce healthcare costs. The survey also examines the level of compliance among patients treated with these therapies. Only

5.7% of patients refused treatment with biosimilar drugs; this refusal has been caused by fear of side effects (38.2%), fear of it being less effective than their current treatment (14.6%), or both (25.5%). It is important to underline that overall 6.5% of patients refused treatment with biologic drugs, due to fear of side effects (45.5%), but also due to previous ineffectiveness of this type of treatment (34.9%).

As stated by Dr. **Ambrogio Orlando**, IBD Operational Unit Supervisor at the A.O. Ospedali Riuniti “Villa Sofia-Cervello” hospital in Palermo, “the use of biosimilar drugs is an important and vital matter, especially with the ongoing researches and developments of new, extremely expensive treatments for IBDs leading to the necessity to free economic resources in order to sustain IBD healthcare costs. The survey data show extremely useful information that must be taken into account when deciding on the future strategies to improve patient awareness and their knowledge about the existence and employment of biosimilar drugs. Compared to Northern European countries, where the employment of biosimilar drugs reached 80-90%, Italy

“Less than 2 out of 10 patients signed the informed consent form”

is still far behind. Given the imminent deployment of new IBD biosimilar drugs, I believe in the necessity of an information campaign aimed at improving patient knowledge on this topic, in coordination with patient associations and Scientific Societies”.

Following this survey, IG-IBD (a scientific society and an important reference in dealing with the management of IBD patients) highlighted how “biosimilar drugs should be considered as efficient and safe as their originator, if this equivalence has been proved by studies carried out according to EMA rules. Consequently, the extrapolation of indications is

acceptable if the biosimilar drug passes one or more of the obligatory tests needed for the approval of its originator and if the regulatory agencies approve it for the same therapeutic indications”.

As stated by Professor **Alessandro Armuzzi**, general secretary of IG-IBD, “patient knowledge about biosimilar drugs should be promoted through education and refresher courses, aimed at encouraging informed choices, with the help of patient associations when possible. A biosimilar drug approved by the EMA should be considered as safe as the originator drug; however, extremely large scale observational studies are still necessary to monitor its long term effects. If biosimilarity has been confirmed, every biosimilar drug can be considered interchangeable with its originator, thus switching from the originator drug to a biosimilar with the same molecule is acceptable. However, switching from a biosimilar to another or switching multiple times should be avoided in absence of any direct and specific proof of the effectiveness and safety of this process. Automatically switching a patient’s therapy should be avoided, too: since the physician is the only person accountable for the prescription of a biosimilar drug, this responsibility cannot be delegated to another stakeholder. The switch from an originator to a biosimilar drug should follow an adequate patient education process and require the patient’s consent”.



Left to right: Prof. Armuzzi, General Secretary of IG-IBD (Italian Group for the study of IBD), Salvo Leone (AMICI Director and EFCCA President), On. Elena Carnevali, XII Social Affairs Commission of the Chamber of Deputies, Ester Maragò, journalist

Advanced Therapeutics within **Everyone's Reach**

Celltrion Healthcare is a biopharmaceutical company committed to delivering affordable quality therapeutics for patients



“I want to be the voice of people with IBD”

Interview with Anna Hakala, a Crohn’s patient from Finland who is managing a Facebook group for people with IBD

Anna’s IBD Journey: It took Anna an incredulous 19 years to finally get diagnosed with Crohn’s disease!! Since her birth she was having problems with her bowels and throughout the years she saw many doctors without luck and even being accused of seeking attention or faking symptoms.

It was only at the age of 19, once she got pregnant and when her symptoms became really bad, that she has finally diagnosed with Crohn’s disease. Since then she had 23 surgeries, 3 ostomy bags, only 1 meter of bowel left and many hospital visits not knowing whether she will be alive the following year.

Question: Anna, what motivated you creating a Facebook Group for people with IBD?

The whole idea started when I came out of hospital and I was looking for a place or group of people to talk to who could understand what I am going through and how scared I was. I couldn’t find anything so I decided together with my mum to start such a group on Facebook where we could talk to each other. At the beginning we were only 10 people but now the group has become very big. We are over 4000 people currently.

I think the reason for this is because I have been very open about my disease, I have been talking on TV about it and there have been lots of articles and interviews about my story. You see talking about ‘poo’ is a taboo and it feels embarrassing, but I wanted to tell other people, especially young people, that it’s okay and that they are not alone.



I was once alone and very scared, I stayed at home, I was afraid, I didn't talk to anybody and I didn't have any friends. I didn't want anyone else to go down that road and I wanted everybody to know that there is somebody who understands you, somebody who has gone through the same and who can make that road easier. I wanted to hug younger people and walk with them. This was the only way I could think of helping since I am just a person and I don't have much money to do something big, all I could think of was being there for them.

Question: What have been the reactions and feedback from people?

The reactions have been very positive, what's more, there are now doctors and nurses who tell newly diagnosed patients to check out my Facebook group. In hospitals they know about my group which has grown literally by word of mouth and I haven't had the need to use any type of advertisements to make the group known. Just me speaking out loudly has been enough.

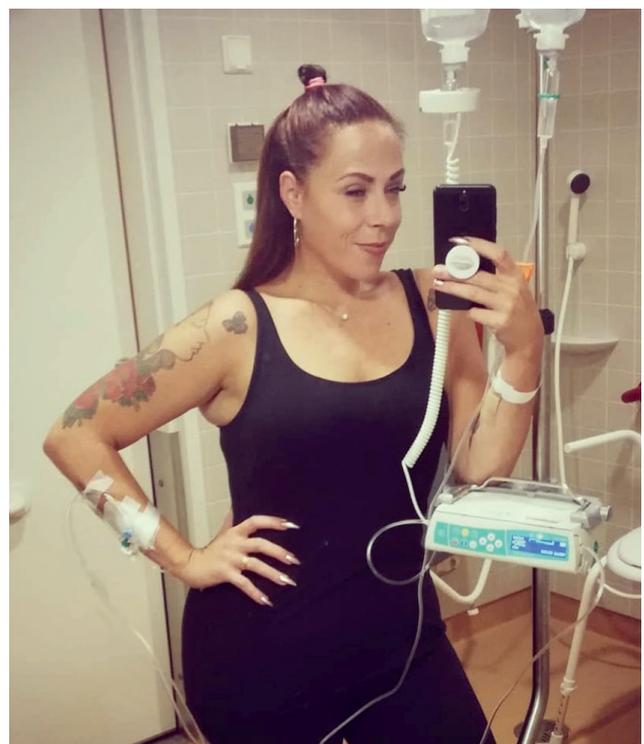
The group, which is a closed group, runs very smoothly and it's perceived as a very supportive environment. Of course, we had some problems with people trying to advertise some miracle cures, so I have been quite firm about our FB rules. The rules are that we can only talk about the disease and/or about medication prescribed by doctors or the Finnish government.

Amazingly we had no arguments and no teasing in the group and people feel very supported by the group. I have been told by members that the group feels like a family they needed, a family that understands even without words.

We get new members that know nothing about the disease and even if they ask the same questions, we are all very supportive in answering and explaining as best as we can. We always try and give hope to everyone.

I really want to thank all those 4000 people because they are all so friendly to each other.

“I was once alone and very scared (...) I didn't want anyone else to go down that road! I wanted everybody to know that there is somebody who understands you, somebody who has gone through the same and who can make that road easier”



Anna during one of her many visits to hospital

Question: Since this group has become so big has something changed in the way you manage the group?

Not really, I am doing more or less the same as I did in the beginning. Obviously, I have to read more and spend every day checking what is happening and what is being written in the group. Luckily my mum is helping me with this.

Otherwise the group is really working by itself. We are talking about a lot of issues such as IBD and sex, marriages, aging, dating, everything really. I don't have to manage anything, it's working by itself and that's the amazing thing.

What has changed is that we are now only accepting new people that have already been diagnosed with IBD. The reason is that we feel it might be harmful for those people who haven't been diagnosed yet as they might get scared by some of our stories and might end up not going to the doctor. Of course, there are many happy stories in our group but there are also some difficult stories and could be difficult to digest.

Question: What are your plans for the future?

I have lots of plans. Mainly I want to talk more in public about IBD. I also want to talk to doctors of what it's like to live with this disease and how to best approach patients about this.

I want to be the voice of those patients who are too scared to say that they are afraid!

I want to tell people that even though we look fine, we are sick. For example, when using a handicap toilet people might react badly because our disease is not shown in our face but it's there! You don't have to look sick to be sick.

Basically, I want our group of people to have more rights and to make their life easier!!



Raising awareness about IBD in the press

PEOPLE COME FIRST AT FERRING

FERRING
PHARMACEUTICALS

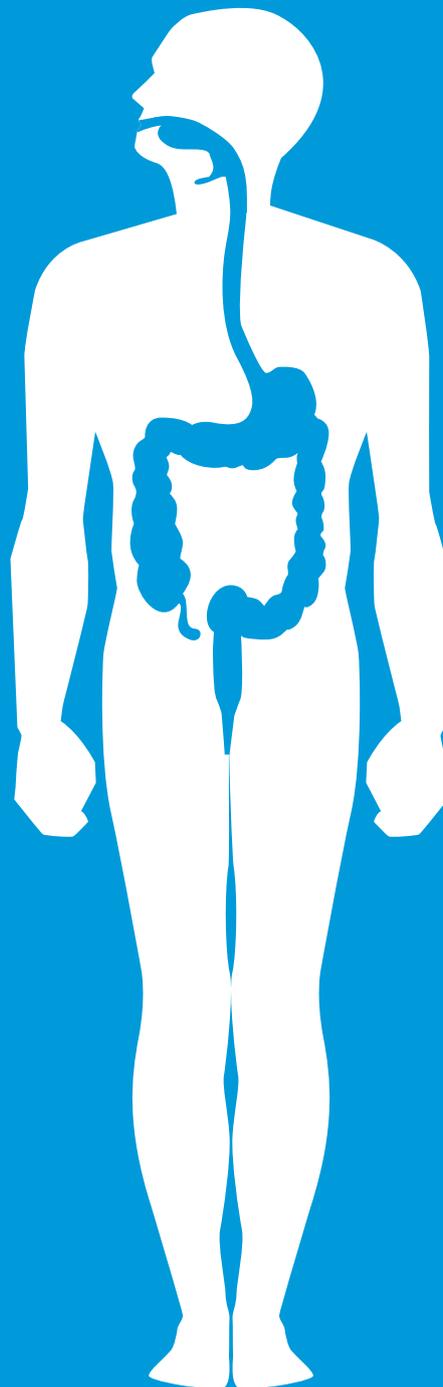
Making a difference to people's health and quality of life, today and tomorrow.

TODAY

FERRING ENJOYS A STRONG REPUTATION WITHIN THE INTERNATIONAL GASTROENTEROLOGY COMMUNITY.

Our research activities have resulted in the development of many effective products that help improve patients' lives.

FERRING BELIEVES IN THE VALUE OF SHARING KNOWLEDGE AND WORKS TOGETHER WITH PATIENTS TO RAISE THEIR VOICE.



TOMORROW

OUR COMMITMENT TO RESEARCH: LIVER DISEASE, INFLAMMATORY BOWEL DISEASE, FUNCTIONAL BOWEL DISORDER.

FERRING is a research driven company that invests heavily in its research infrastructure both in terms of people and technology.

PLEASE VISIT
WWW.FERRING.COM

Everything you wanted to know or didn't know about "Home Parenteral Nutrition"

The Medical Nutrition International Industry (MNI) - with the support and feedback of organisations representing patients and healthcare professionals, including also EFCCA has consolidated a list of questions and answers to better inform patients and their families, carers, homecare providers, healthcare professionals, decision-makers and the general public at large on the use of home parenteral nutrition.

Intravenous feeding (read "[parenteral nutrition](#)") may be a life-saving therapy for patients with different illness conditions that cannot meet their full nutritional needs only through oral or enteral feeding.

Home parenteral nutrition - i.e. intravenous feeding administered outside the hospital, either at home or in a nursing home - may improve patients' quality of life and support their ability to perform daily activities.

For whom would home parenteral nutrition work? Can a patient on home parenteral nutrition shower or take a bath? Can a patient travel with it?

For instance, home parenteral nutrition may allow patients with chronic or acute diseases to manage their needs for additional nutritional intake outside the hospital. For certain patients this may mean in practice:

- Less pressure to eat in sufficient quantities
- Ability to perform daily activities, including family life
- Ability to work
- Ability to travel
- Increased independence in daily life

Many of these questions and issues are addressed in the Medical Nutrition International Industry (MNI) Frequently Asked Questions list. In the words of Léa Coulet - MNI Executive Director: *"We believe that*

home nutritional care has a critical part to play for improving quality of life in patients whose conditions require parenteral nutrition. Not only that parenteral nutrition itself could increase therapy tolerability and success, home parenteral nutrition may improve patients' quality of life and may be more cost-effective compared to parenteral nutrition delivered in hospitals."

MNI will also soon launch a website dedicated to home parenteral nutrition to unfold more information about it and to share patients' experience on its use, benefits and safety features. Stay tuned!

For more info please visit:

<http://www.medicalnutritionindustry.com>

Discover the MNI factsheet on Medical Nutrition: https://medicalnutritionindustry.com/files/user_upload/documents/mni-factsheet-final-corr.pdf



Stakeholders round table discussion on HPN, Munich, 22 October 2018

The rising tide of falsified medicines - a major public health threat

The Alliance for Safe Online Pharmacy (ASOP EU) is on a mission to create and promote an environment that enables patients to safely buy their medicines online in a space permitted by law. Mike Isles, Executive Director ASOP EU explores this further.

The manufacture and distribution of fake medicines is an enormous and growing public health risk with an untold cost to lives. Vast profits are made by organized criminal gangs who will use the proceeds to support other criminal activities.

Some startling facts:

- Up to a third of the world's prescription medicines are substandard or falsified, and two-thirds in some developing countries
- Worth \$200 billion a year, the market now eclipses almost everything else in the underground economy
- 35,000 websites are aimed at the world wide public at any given moment and 96% are operating illegally
- 20 new websites selling prescription medicines are launched every day
- 89% of illegal online pharmacies don't require a prescription for a prescription medicine

Evidence shows that consumers and patients are becoming increasingly reliant on, and trusting of, the Internet, which also provides the channel to buy illegally distributed fake medicines, in the majority of cases by an unaware public.

As shown in a recent ASOP EU research study, up to 65% of people going online to buy a medicine do so without prior knowledge of the fact that 96% of

websites selling medicines are operating illegally.

This market is a global one with the Internet allowing a rapid and seamless buying of medicines and so Education is a key success factor in solving this patient safety problem because there are up to 35,000 illegally operating websites that target consumers and patients across Europe and the world.

To raise public awareness [ASOP EU is running a campaign](#) in 5 European countries which contains very useful information to help inform the public about the phenomenon of fake medicines.

A 34 country wide initiative involving the youth and under the umbrella of Youth Internet Governance Movement will now include educational activities around fake medicines designed to educate the youth of today about falsified medicines was being developed.

Delivering training and capacity building to young people and engaging with them to promote their active participation will mean that young people who are active on the Internet can learn about online patient safety and disseminate this through their social media networks.

Patients and consumers alike need to understand how to buy medicines safely from the Internet.

By following some useful rules will help ensure this happens.

Do not buy from an online pharmacy that...

- Does not have a licensed pharmacist or physical address and a telephone number that works
- Offers “bulk discounts” or “amazing results”
- Does NOT REQUIRE a valid prescription for prescription medicines - this immediately tell you that it is operating illegally

- In Europe if it does not include the common logo on the website which looks like this with your country flag the BEWARE



For more info please visit: <https://buysaferx.pharmacy>

The IBD Nurse Education Programme

The ECCO IBD Nurse Education Programme was introduced in 2018. Prior to embarking on the development of the programme, N-ECCO undertook a survey regarding the IBD nurse role in 2014 and found very large variation across Europe, with the role still being in its infancy in some countries. The level of education also varied. A scoping exercise was done to see whether there was a need for an educational programme.

A total of 140 responses were obtained from a mix of clinical IBD nurses, nurses who reported that they cared for patients with IBD but whose role was not specifically IBD care, and research nurses. There was overwhelming agreement on the need for this type of programme and over 60% said that they had no accredited IBD course available to them. In all countries the largest provider of IBD training was the pharmaceutical companies.

Based on the N-ECCO survey and the scoping exercise, EduCom and N-ECCO developed the IBD Nurse Education Programme. The course is fully funded by ECCO, including the cost of a one-week

visit by the participants in their chosen IBD centre. The course will cover aspects of IBD which are relevant to all IBD nurses. It will address both fundamental and advanced IBD care and also offer supportive clinical and nursing mentorship and experiential learning through a visit to a centre of IBD care either in the country of practice or in Europe.

The course is organised into monthly modules, covering a 6-month period, and will start with a face-to-face (F2F) meeting. The course will end with a final F2F meeting to discuss the learning that has been achieved as a result of the course.

For more information please visit:

<https://www.ecco-ibd.eu/publications/ecco-news/item/the-ibd-nurse-education-programme.html>



Pfizer Inflammation & Immunology

Building on a heritage of more than 60 years, Pfizer I&I is a leader in transforming the lives of people with inflammatory and autoimmune conditions.

The leadership of Pfizer I&I is demonstrated by the development and delivery of medicines to help address the unmet needs of patients living with certain rheumatology, medical dermatology and gastroenterology conditions. Pfizer provides resources to help educate people living with these conditions so they can better understand how to get the most out of their treatment and care. We also provide services to ensure that patients have access to the benefits of our breakthrough scientific advances.

With multiple potential regulatory milestones worldwide, our expansive research program and pipeline will sustain our momentum and strengthen our ability to put more I&I patients first around the world.



Current Practices in Ileal Pouch Surveillance for Patients with Ulcerative Colitis: A Multinational, Retrospective Cohort Study

A recent study on current practices in Ileal Pouch Surveillance for Patients with Ulcerative Colitis which has been recently published in the *Journal of Crohn's and Colitis* (24 December 2018) aims to better understand surveillance practices of ileal pouch-anal anastomosis.

A restorative proctocolectomy and ileal pouch-anal anastomosis (IPAA) is a surgery where the colon (large intestine) and rectum are removed and a "reservoir" for storing stools is created using the small intestine to replace the colon. The reservoir, often called J-pouch because of its shape that resembles the letter J, is then connected to the anus.

This surgery is an option for ulcerative colitis (UC) patients who have failed medical management, for some Crohn's disease patients as well as patients with e.g. some types of colon cancer.

As there are no universally accepted guidelines for the monitoring of UC patients after the IPAA surgery and also no validated quality assurance standards for pouchoscopy (endoscopy procedure to examine the pouch), the authors performed a retrospective cohort study at five IBD referral centers by reviewing records of 272 patients who

underwent an IPAA surgery for UC or Inflammatory Bowel Disease Unclassified (IBDU).

It was found that 35% of the 272 patients had never had a pouchoscopy; 70% had never had a pouchoscopy only for follow-up, and even 12% of high-risk patients had never had a pouchoscopy. Two adenocarcinoma cases were identified, both in low-risk patients.

The authors found that patients under the care of surgeons seemed to be more followed up, however incomplete reporting was much more common amongst surgeons than gastroenterologists.

The authors conclude that there is wide variation in the monitoring of UC and IBDU patients following up an IPAA surgery. They also point out that the cancer rate in patients who were considered low-risk was higher than may have been expected. The authors therefore agree with previously

published recommendations that a pouchoscopy should be performed one year after the IPAA surgery, and findings in all parts of the pouch should be documented and biopsies taken.

Link to the scientific article:
<https://doi.org/10.1093/ecco-jcc/jjy225>

Augmented Endoscopy for Surveillance of Colonic Inflammatory Bowel Disease: Systematic Review with Network Meta-Analysis

A recent systematic review with a meta-analysis has been published on 28 December 2018 in the Journal of Crohn's and Colitis. The review aims to assess the best strategy for endoscopic monitoring IBD in the large intestine.

Surveillance (monitoring) of IBD patients is commonly considered important because of the high dysplasia and cancer risk. International guidelines, however, do not provide uniform recommendations on how to do this. The authors therefore performed a systematic literature review with a meta-analysis (a statistical analysis combining the results of multiple scientific studies) to assess the best strategy for endoscopic monitoring IBD in the large intestine.

Following a search through several medical databases, studies comparing white light endoscopy (WLE) and augmented endoscopy (AE) in the detection of dysplasia (abnormal cell growth but not yet

cancer) or neoplasia (excessive cell growth that is not under physiologic control) in colonic IBD were identified. Furthermore, the authors carried out a sub-analysis between dye-spray chromoendoscopy (DCE), narrow-band imaging (NBI), I-SCAN, full-spectrum endoscopy (FUSE) and auto-fluorescence imaging (AFI). Twenty-seven studies (a total of 6167 IBD patients with dysplastic lesions) were included in the analysis.

The authors found that AE, DCE and AFI were more likely to detect dysplasia than WLE; I-SCAN, NBI and FUSE, however, were not better than WLE. Dysplasia was found in 17.3% of targeted biopsies and 0.33% of random

biopsies. In the statistical analyses, however, no variable was found that would have impacted the efficacy of the AE technique. In a network meta-analysis, DCE - but no other single technique - was found significantly better than WLE in detecting dysplasia. The authors conclude that in this analysis, DCE was associated with a higher likelihood to find dysplasia than WLE and recommend therefore chromoendoscopy as the best endoscopic technique for monitoring IBD.

Link to scientific article:
<https://academic.oup.com/ecco-jcc/advance-article-abstract/doi/10.1093/ecco-jcc/jjy225/5259264>

EFCCA Contact Details

**Rue des Chartreux 33-35
B -1000 Brussels Belgium
Tel/Fax: +32 2 540 8434**

Registration: 1096/97
Revised 22/2/2006
No. 459814543

Chairman:
Salvo Leone
Salvo.leone@efcca.org

CEO: Luisa Avedano
Tel: +32 483 371 194
luisa.avedano@efcca.org

Honorary Secretary and
Vice President: Ciara Drohan
ciara.drohan@efcca.org

Treasurer:
Marko Perovic
marko.perovic@efcca.org

Editor-in-chief: Isabella Haaf
EFCCA Deputy Director
Tel: +34 606 849 937
bella.haaf@efcca.org



A world free from immune and inflammatory diseases. **That's our vision.**

At Janssen, we like to dream big. And our hope for immune and inflammatory diseases is no exception.

Through science and collaboration, we look to transform how diseases like rheumatoid arthritis, Crohn's disease, plaque psoriasis and asthma are treated today—and prevented tomorrow.

We dream of a future free of the pain and challenges for the one in 10 people worldwide living with these diseases. We are relentless in our pursuit of advancing science and delivering breakthrough medicines to make a difference in their lives.

But bringing forward new solutions isn't enough. We want to shorten the journey from diagnosis to treatment. And through our education and awareness programmes, we're here to help forge that path.

We are Janssen. We collaborate with the world for the health of everyone in it.

Learn more at www.janssen-emea.com



The image depicted contains models and is being used for illustrative purposes only.

Janssen Pharmaceutica NV